Family Perspectives:
Cultural/Ethnic Issues Affecting Children with Special Health Care Needs

Educational Fact Packets for

Health and Human Service Providers

This material was supported in part by: Project MCJ-355085 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services

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P.O. Box 788
Bernalillo, New Mexico 87004
Phone: (505) 867-3396 FAX: (505) 867-3397

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Acknowledgments

These educational fact packets are the result of the combined efforts, commitment, and enthusiasm of the Opportunities for Professionals and Families to Understand Strategies for Cross-Cultural Communication (OPUS) Project staff, the families who shared their experiences and perspectives, the consultants who provided us with their knowledge and expertise, and the professionals who shared their perspectives and gave us feedback on our materials. We thank all of them for their help in making this work a success. We would like to acknowledge some of the key people who worked with us. They are:

Deborah A. DeLaRosa, OPUS Project Associate
Southwest Communication Resources
Albuquerque, New Mexico

Manuel Green
Children's Medical Services
Albuquerque, New Mexico

Kristine S. Maltrud
Health Planning Associates
Albuquerque, New Mexico

Sandra Dogens Barney and Karen Divinity
Project HOPE
New Orleans, Louisiana

Martha Gorospe and Jeannie Manuelito
EPICS Project
Bernalillo, New Mexico

Connie Baca
Sandoval County EOC
Bernalillo, New Mexico

Rebecca Viers
Early Childhood Education Program
Pueblo of Laguna, New Mexico

Christine Gryniuk
Taos County ARC
Taos, New Mexico

Dorothy Yonemitsu
SEADD Project
San Diego, California

Ellie Valdez Honeyman
Colorado CSHN Program
Denver, Colorado

Josie Thomas
Institute for Family-Centered Care
Bethseda, Maryland

David Allen Jones
Institute on Cultural Dynamics and Social Change
Rochester, Minnesota

Elizabeth Chung
Ohio Health Department
Columbus, Ohio

Felicia Jordan-De Silva
Project UPTOWN
Detroit, Michigan

Carol Johnson
Project UPBEATT
Detroit, Michigan

Jenny Ap
Touchstones
Seattle, Washington

Joseph Garcia
Touchstones
Seattle, Washington

Steve Elliott
Freedom Child Development Center
Seattle, Washington

Denise Larson
Kwiat Child Development Center
Seattle, Washington

Valerie Nelkin, OPUS Project Evaluator
Bear Enterprises Ltd.
College Park, Maryland

THANK YOU ALL!

Randi Suzanne Malach
Project Director

Family Perspectives: Cultural/Ethnic Issues Affecting Children with Special Health Care Needs

Purpose

How can service providers learn more effective ways to provide family-centered, culturally responsive services to families? In today's rapidly changing health care environment, professionals are challenged to develop partnerships with families while taking on larger caseloads and limiting face-to-face time with the people they serve.

This fact packet was developed in response to requests from health care professionals who provide services to children with special health care needs. These service providers wanted to know more about the perspectives of families from diverse cultural backgrounds. They also wanted an easy-to-read, concise summary of the key facts known about barriers that inhibit cross-cultural communication and the methods for overcoming them.

The purpose of these fact packets is to provide information which will:

- Increase awareness of the obstacles and potential barriers that cultural differences can present during communication between families and providers;
- Facilitate effective ways for overcoming barriers that do exist;
- Facilitate changes which will help professionals and families to form partnerships which will ultimately improve the child's health and the family's ability to care for their child.

The intended audience for these materials is health, education and human services providers, including physicians, nurses, therapists, early interventionists, educators, social workers, administrators, and support staff.

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Family Perspectives: Cultural/Ethnic Issues Affecting Children with Special Health Care Needs

"We're supposed to be working together as partners for the care of the child. You have to address our family in order to help our child. Remember that some of the things that you want to do for our child, may not be seen as a priority by our family." (Parent)

Background

This document summarizes the significant results of a three-year project, known as the OPUS Project. This project examined family and professional perspectives about cross-cultural communication. Through their participation in the project, families and providers identified cross-cultural factors which impede effective communication and service delivery. More importantly they identified methods for *improving* cross-cultural understanding, communication and collaboration. This fact packet was developed from that information.

Information was collected in several ways. The primary method was the use of family focus groups. These groups were conducted with families of children with special health care needs. Nineteen groups were conducted in nine states involving more than one hundred and twenty-two different family members. Those families shared their experiences and their feelings. They gave examples of the obstacles they encountered, as well as the successes they had experienced while accessing services.

The project involved numerous consultants from the targeted cultural-ethnic populations. Information on cultural issues was also obtained from a Task Force which included state policy makers, service providers and families. Both the Task Force and the consultants provided feedback on the information gathered and contributed to the development of the recommendations found in this document.

The Family Perspectives information sheets include *significant quotations from the families* who participated in the focus groups and consultants from the particular cultural-ethnic groups. *It should be remembered that despite the fact that this information is representative of some families of children with special health care needs living in various part of the United States, there is great variation between families and communities.*

The Recommendations section contains a summary of principles of effective cross-cultural communication and examples of specific health care situations in which differences in cultural-ethnic values and beliefs frequently occur. Following each principle and situation are practical recommendations for improving provider understanding and responsiveness to families whose culture or ethnic background maybe different from their own.

Family Perspectives: Cultural/Ethnic Issues Affecting Children with Special Health Care Needs

Introduction

Although all families who have children with special health care needs face many challenges as they seek services, families of ethnic or culturally diverse backgrounds often encounter additional obstacles. The greater the cultural-ethnic difference between the family and the service providers, the more ominous those obstacles can become.

The ethnic-cultural composition of our communities is becoming increasingly diverse. In order to be effective, health care providers must learn culturally appropriate ways to communicate and form partnerships with families whose cultural/ethnic heritage is different from their own.

> *"For the longest time, our society assumed that the United States was mono cultural and monolingual. They did not appreciate culture and diversity."* (Parent)

Historically, our health service system has not demonstrated appreciation for the diversity of the families. During the past decade, health care systems established goals to provide family-centered and culturally-responsive services. In order to be family-centered and culturally responsive, service providers often must make behavioral changes which can conflict with their professional training and their work environment. Large caseloads, time lines, and cost containment measures further inhibit implementation of these goals.

Often health care providers are not aware of the significant influence of culture on their interactions with families they serve and co-workers. Culture influences how a family perceives illness and disability, as well as, the actions they choose to take. In some cultures, the family will go to a healer from their cultural community prior to seeking services from the medical community. When the family decides to access medical services, it is critical that the service provider be sensitive and responsive to their cultural-ethnic beliefs and customs. Families frequently are offended by provider actions founded on biased beliefs or incorrect information.

> *"Some professionals make negative statements about our traditional healing methods. They have washed off important markings or removed things placed on the child by the healer. They do not ask the family. They do not show respect." (Parent)*

Cross-cultural differences can create obstacles to effective communication. When providers demonstrate culturally sensitive and responsive behavior, they are able to develop family-provider partnerships based on mutual trust and respect. The time needed to do this seems long in the beginning, but the benefits last a life time.

Family Perspectives on Cultural-Ethnic Bias and Stereotypes:

African American families report that they continue to struggle against subtle and overt discrimination. Families involved in the focus groups, and others with whom we spoke, confirmed that they frequently experience selective discrimination. They expressed deep concerns about the way the media and government portrayed African American people as poor, uneducated and frequent users of drugs or alcohol.

> *"We're stereotyped and the media does not do anything but perpetuate it. And, not only the media but the government . . . They automatically assume that they are looking at an uneducated, black welfare mother who does not know enough to ask any decent questions . . . And it takes them a while to kind of get past the color issue . . ."* (Parent)

> *"It's very difficult for me when I come across that subtle racism. Many of the standardized tests have white middle class values. So they're not necessarily culture free . . . I remember reading one of my daughter's reports that said, 'Young healthy Black child apparently given clean clothes to wear.' And, I was outraged by that!" (Parent)*

Family Perspectives on Communication Interaction and Services:

Families reported that because providers think that all African American/Black people are poor, they do not tell these families about *all* the resources available. No matter what their income level, families want information about all the resources available for their child so that they can make informed choices.

> *"The health care providers don't tell you about these resources. Because they only tell certain people. Because they think we don't have the money to pay."* (Parent)

African American/Black families expressed concern about the frequency with which medications are prescribed for their children. They stated that because of the drug problems in their communities, they worry about their children using even prescription drugs. When their children need medications, they want providers to explain why it is needed, how it will benefit their child and what the side effects might be. When their children have behavior disorders, such as hyperactivity, they want providers to try all other interventions first. Medication should be the last resort.

> *"I asked the doctors, ' Why should my child be medicated . . . and start that process of being on drugs, you know, at such an early age?' And why are they doing this? And they hadn't even looked at the whole picture . . . . But I think if they would have more respect for our cultures . . . if we had doctors from our cultures that we . . . that could*

relate to us maybe they wouldn't give these drugs. Maybe they'd think twice." (Parent)

Families expressed concern, confusion and discomfort with the numerous questions that providers ask, particularly case histories.

"*I don't think your past medical history should have anything to do with what's going on with your child . . . If you bring him to the doctor . . . all their focus and interest should be on what's going on with that child then." (Parent)*

"We have a tendency to be a little bit more private . . . . that kind of stuff we kind of hold in the community ." (Parent)

Family Perspectives on Cultural Strengths:

African American/Black families asked that providers recognize their efforts as much as their achievements. For example, when a family arrives late for their appointment, the staff admonishes them. If they had asked and listened, they might have learned that this mother took four buses with five children just to get to the appointment. Her efforts and success in getting to the appointment should be recognized.

Both mothers and fathers discussed the role of fathers, including the historical background, the present situation, and changes occurring.

"Well, you know, in our community it goes back hundreds of years . . . this deprivation. Taking away Black fathers . . . it started there. Black fathers weren't born with the notion in their head to abandon their families. That was a part of a slave mentality that . . . grips the African American family and that was perpetuated upon them . . . Families were split up . . . . It leaves a scar that takes a long time to heal . . . . I'm not the stereotypical angry Black man I used to be, but then I understand to make change you have to understand the system . . . to make the system work with you." (Parent)

Families view their spirituality as a strength. Yet, they often encounter providers who disparage their spirituality. They believe their spirituality provides support and gives their family strength. It should be recognized as a family strength.

"The way I was raised, you took God first. And it supposedly is a stereotype of our culture that we are a 'church driven' people. You know what I'm saying? But it helps me get through a lot of things . . . . This is not a statistical thing or a genetic thing, but you were given this for a very great purpose." (Parent)

"You know our family still believes in miracles, that miracles can happen. And that's the first place they go is to their knees." (Parent)

African American families expressed interest in providers receiving training in their communities and working with their community and church leaders, as well as grass roots organizations already serving the community. They wanted providers to join with them to celebrate and publicize child and family achievements and successes.

Hispanic/Latino Family Perspectives Page 1

Family Perspectives on Cultural Bias and Stereotypes:

Often non-Hispanic people do not realize that there are many Latin American countries in which Spanish is spoken. Hispanic/Latino families range from new immigrants/refugees to descendants of families who have lived in this country for generations. Many stereotypes are based on what people think Hispanic/Latino people should be like. For example, in Louisiana dark complexioned families from Central America reported that they are often mistaken for African Americans because their skin is black.

> *"They often mistake us for African Americans because our skin is so black. They say, African Americans don't usually speak Spanish. How is it that you are black and speak Spanish?'" (Parent)*

Families reported many forms of discrimination.

> *"My son had to be hospitalized at seven . . . when I called in to tell them who he was . . . he has a white last name . . . .When I walked in the door, they looked at me and they looked at him. They said wait a minute! And from the time we walked in that door, you might as well forget it." (Parent)*

A big concern expressed by many families, was the negative perception of Hispanic fathers. Families talked about the traditional role of the father as a provider, and the mother as a care giver.

> *"You see 'macho' has some very negative connotations, but uh . . . initially the word 'machismo' was a very positive and . . . it was a compliment. . . . It was the sense that the father was there and was also giving strength within the family so . . . it was viewed as very loving, in a male sense." (Parent)*

> *"Look at me without using those glasses that say . . . 'Macho Hispanic Male', and if you say something he'll go off. I want them to see me as my son's daddy." (Parent)*

> *"It really bothers me when they ask me, 'Doesn't your husband ever get involved?' And I going, you know, he's working three jobs. He's there when I need him. If I need to ask him for money for therapy, somehow he'll scrounge." (Parent)*

Family Perspectives on Communication Interactions and Services:

Language differences create discomfort and confusion for Hispanic families.

"Most providers speak at 90 miles per hour and I'm hearing it at five miles per hour and understanding it at two miles per hour" (Parent)

"After a while I just got so frustrated . . . I cannot say anything else. They have lost me. I don't understand." (Parent)

Families also discussed a variety of concerns related to the use of interpreters. Providers frequently use interpreters who speak Spanish, but are not bilingual-bicultural and trained in medical terminology, concepts and confidentiality. An interpreter who is not bicultural may not know that in many Latin cultures, it is inappropriate to be totally honest with the family about health issues. For example, if someone has a terminal illness it is inappropriate to tell that person and sometimes their family. The speaking of those words will affect the future and destroy all hope for the family. A bicultural interpreter will be uncomfortable if a provider asks to have this type of information explained. This situation can create conflict and misunderstanding. Providers and interpreters must work together to find culturally appropriate ways to explain sensitive information.

Although it is common for the extended family to be involved in the health care of the child, many providers are reluctant to include them.

"When I asked the doctor, 'I want someone to explain to my family what's wrong with my kid . . . Let's have a meeting.' And we went to the hospital . . . our whole family, and there's a lot of us. We took everybody and they . . . I mean the hospital just about freaked out on us . . . 'Is this all the family?' And I guess they were not expecting so much, but it was a whole room full and there were still some missing." (Parent)

Most Hispanic families prefer formal interactions with providers they do not know. As they become comfortable families may begin to use humor. They appreciate a provider who will laugh with them, but not initiate jokes.

Family Perspectives on Cultural Strengths:

Family is very important in Hispanic/Latino cultures. Large families are valued. There is a very strong love for children. Children are allowed to grow and develop at their own pace. A child with a disability is perceived as a blessing. The entire family is involved in raising children.

"Providers often ask me why Mexicans have so many kids. They want to know how we can afford them. Providers only look at the economics. They don't understand that wealth is measured in many ways. In our family wealth is measured by how many people surround you at the dinner table." (Parent)

Although having a child with special health needs can be very difficult for a family, strength and support come from their own family and spirituality. Families want providers to understand and respect the value they place on spirituality in their lives.

"I realize my daughter wasn't going to change, and so . . . my mother suggested let's go to Chimayo, and we pray . . . . I brought back dirt, and I spread it all over my daughter. And I got milagros, and I went through this whole process . . . . And one doctor asked, 'Why the heck are you doing that?' . . . I said, 'I need that part for me to continue to be strong. I need that. I need to be in touch with God and my spirituality, because there is nothing else right now. They're not giving me answers." (Parent)

American Indian Family Perspectives Page 1

Family Perspectives on Cultural Bias and Stereotypes:

American Indian families participating in the focus groups, spoke of the variety of stereotype beliefs many non-Indian people have about Indian people.

"People have a stereotype of what Indian people are supposed to be like. They look at us as too ignorant to understand the answer. They assume all Indians drink too much." (Parent)

"There is also the stereotype that all Indians are like those in the Southwest. We're from Wisconsin. We aren't all the same." (Parent)

"I'm uncomfortable with providers who think being Indian is stylish, and also those providers who pity us." (Parent)

Family Perspectives on Communication Interaction and Services:

Families reported that translating written material into Indian languages usually does not help. Verbal interpretation and creating audio tape recordings often do help families. Even though some tribes have a written language, few Indian people were taught to read and write their native language. The majority of Indian people went to schools in which they were taught only English. Because there are so many different Indian languages, there is a high need for interpreters who are bilingual-bicultural, and respected by the community. Families stressed that interpreters should be trained on medical terminology, concepts, and confidentiality.

" Imagine our situation with the English that is spoken in the doctor's office. The terms they are using start off in Latin. Then they get translated into medical English. Then they try to put it into common English. Then it is further translated into my language, so that my family and I might be able to understand what is being said." (Parent)

Many Indian families reported that they are taught to show respect by listening, avoiding eye contact, and not asking questions. Providers often misinterpret these behaviors as meaning that the family doesn't care, isn't listening, or agrees.

"Indian people are quiet. To the white man this seems to mean less educated." (Parent)

Humor is important and may be used by the family as they get to know the provider. Although the family may initiate the joking, the provider should not. Providers should follow the family's lead laughing with the family and being able to laugh at themselves.

> *"Our doctor is someone you can talk to and joke with. We tell those other service providers a joke and they look at you strange. When we invited our doctor to our POW WOWS, he came. That meant a lot to us." (Parent)*

When a family member is sick, many Indian people go to traditional Indian healers who provide them with support and traditional holistic methods to promote healing.

> *"Most Indian families go to the "western" doctor for a second opinion. They go to the medicine man first. The family helps arrange the session with the medicine man. The medicine man gives advice and helps the family with the problem." (Parent)*

Traditional healing practices are typically non-invasive. Invasive medical procedures such as drawing blood or surgery are inconsistent with many Indian cultural practices. Before giving consent for these types of procedures, more traditional families must talk first with other family members.

Usually the family will not tell the medical doctor about the Indian healing practices. Many Indian families believe it is better that the medical people do not know. If a family does state that they are doing family or Indian things, it is important for the provider to listen and show respect for the family's decision by supporting their efforts as they go through the process.

> *" Scheduling appointments in advance is difficult sometimes. Our traditional things do not happen on a calendar. When you have to prepare for a ceremony, you miss an appointment. Sometimes you can call and sometimes you can't. They need to understand our culture and be more flexible." (Parent)*

Family Perspectives on Cultural Strengths:

Extended family is highly valued and elders are treated with great respect. Extended family including blood and clan relationships may all be considered part of the immediate family. When decisions need to be made, elders are often consulted. When the parents are young, an elder family member may actually have the responsibility for decisions regarding the child. Children are protected.

> *" We respect our elders. You don't call elderly, dear or honey." (Parent)*

> *"Our family members are going to stay there because it's part of our family culture to be there when people are sick . . . We believe that children, especially, are vulnerable to negative forces . . . so we stay with them and place protective things on*

them." (Parent)

A traditional lifestyle is still practiced and valued by many Indian people who live on reservations. Even families who live in the city will go back to their traditional ways when they return home. In many families that means that they live in communal type living environments, cooking and eating of more traditional foods. Daily activities are not based on clocks. Recipes are not written. Measuring utensils and thermometers are not used. For example, in the Southwest bread is baked in an outside oven, without a thermostat.

Southeast Asian/Chinese Family Perspectives Page 1

Family Perspectives on Cultural-Ethnic Bias and Stereotypes:

The families involved in the focus groups were primarily refugees or new immigrants from Southeast Asian countries and China. They all live in communities with other families who share their culture. Since many came from countries with oppressive governments, they are cautious of government services and of people they do not know. Families are reluctant to sign papers they do not understand. They are also fearful that something may be taken away or some misfortune will occur if they sign a paper. Families stated that they are learning the ways of this country at a slow pace which is most comfortable for them. They expressed concern that non-Asian people are not aware of the great diversity among the different Asian cultures, languages and religions.

" In many agencies they assume that all Asians speak the same language. They don't recognize and learn about the different ethnic and cultural groups that are Asian . . . . Like, they don't know that there are very great differences between the Hmong and Laotian people." (Parent - with interpretation)

Family Perspectives on Communication Interaction and Services:

Asian family perspectives on disability and illness are often misunderstood by medical providers. Interventions which are appropriate for other cultural groups are often inappropriate for these families. For example, in some Asian cultures:

"If a child is born with a disability in our culture, we believe that it is because a grandparent or . . . someone else did something wrong. It could be during the time of the grandparents . . . or even one thousand years ago." (Asian consultant)

"The American way of speaking up and support groups is new to us. Everyone is very private in our culture . . . . If you bring up the subject of being disabled, everyone is uncomfortable and becomes very quiet. This is why we have difficulty. If there is a disability, we withdraw." (Parent - with interpretation)

These families described themselves as a private people with many traditions.

"Our community maintains the traditions and supports its members. Seeking services outside the community or from an outsider is uncomfortable and not always supported." (Parent - with interpretation)

"When a child has a serious or chronic condition, the family will seek the wisdom and assurance of an elder (natural healer-Shaman). The elders use spiritual and traditional treatment methods. These natural healers will, when appropriate, recommend the family go to a medical doctor." (Asian consultant)

Families stated that they prefer to go to Asian medical doctors who speak their language, and understand their culture. Also, these doctors will see them without a pre-scheduled appointment and do not make them wait a long time when they arrive at their clinic.

Traditional Asian healing practices are often misunderstood. For example, bruise marks caused by Asian healing treatments have resulted in child abuse investigations.

"Mothers who do not visit their newborn babies in the hospital are thought to be neglectful. Those providers don't understand that in some Asian cultures, new mothers must go through a traditional cleansing ritual at home after the baby is born, lasting up to 30 days." (Asian consultant)

Verbal and nonverbal communication differences often result in misunderstanding. For example, providers may believe an Asian family agrees, when in fact they do not.

"We have a strong sense of pride. Admitting a mistake or problem publicly results in humiliation . . . . When a service provider speaks it is respectful to nod, smile and say, 'Okay, yes.' It is disrespectful to ask questions or admit that you don't understand." (Parent - with interpretation)

Families reported discomfort with certain provider behaviors which they consider to be disrespectful. They were uncomfortable with informality, such as relaxed sitting posture or the use of first names. In some cultures, it is inappropriate for men to talk about women's health or for children to discuss adult health.

"Some health providers touch our children on the head as a way of showing friendliness. In our culture this is disrespectful. A child's head is considered sacred, and should not be touched." (Parent w/interpretation)

"The doctor wanted our child to interpret for us. This is not a good idea. . . .Children are not supposed to explain to their parents." (Parent - with interpretation)

Asian families are also uncomfortable talking about personal health care issues in front of a stranger. Frequently, providers grab anyone who speaks the language or looks like they speak the language to act as an interpreter. Families believe there is a need for interpreters who are bilingual-bicultural, and trained in confidentiality, medical terminology and concepts. They also stressed that interpreters should only be hired if they are "respected" by the communities being served.

Family Perspectives on Cultural Strengths:

Privacy, honor, humility and a formal manner of communicating are valued.

> *"One time I was given some forms to fill out. As I read, I realized that I didn't understand some of the words and phrases. This was embarrassing . . . so I took the forms home . . . . I look up the words in the dictionary." (Parent - with interpretation)*

Because health issues are considered personal and private, most parents are not interested in support groups. Roles of family members are extremely important. An elder male must be included in discussion and decision making. It may be a father, relative, friend or a community leader. The community provides support and protection for all members. Large families are valued. Elders are respected. Children are protected.

Principles and Recommendations for Effective Cross-Cultural Communication and Collaboration

> *"They want to learn the language . . . a little bit of your culture . . . . And I noticed when they do that, they tend to understand you more better, and they . . . value you . . . . So it's attitude. If the provider sees that as something Bonito, then they want to learn from that and they ask you those questions." (Parent)*

Principle: Everyone has cultural beliefs and values. There are many different cultures and ethnic groups. It is not possible for anyone to learn every nuance of every culture and ethnic group.

Recommendations:

1. Learn about your own culture. How were you brought up? Who made decisions regarding health care in your family? Did your family use non-medical treatments for certain illnesses? How have you changed your values from those of your family? When did you do change your values, and why?

2. Learn about the culture, communication styles and values of your profession, agency, co-workers, and other service providers. Discuss how these factors affect the ways in which you work together.

3. Learn about the cultural values and communication styles of the families and communities you work with. Look for and recognize the similarities, as well as the differences between yourself and these groups, and among these groups. Generally, it is more comfortable to talk about shared beliefs, values, and experiences. Relationships are built on the things we have in common.

4. Be aware of and strive to avoid stereotypic beliefs. Values related to family, culture and community vary greatly.

5. Learn culturally appropriate ways to show respect and gain trust. Understand that time

is needed to build trusting relationships.

6. Learn about the history of the families and cultural populations you are serving. How did they come to live there? Does the family receive support from their cultural community?

7. Identify and use resource people from the community to learn about the culture and community. These people may be parents, elders, church leaders, community leaders, tribal leaders, or people working for grassroots organizations already serving the community.

8. Remember that it is okay to say, "I don't know" or "I want to learn." Learning about people and their cultures is a quest for increased awareness, knowledge, understanding, and sensitivity.

"I think it's important to remember that we're dealing with families that are at various levels of acculturation that. . . . We constantly have to remember that families are at different levels, not only culturally, but by experience." (Asian consultant)

Principle: Many cultural factors impact a family's reactions to and acceptance of health services. Three important factors are:

- ✓ **The perceptions and beliefs of the family and their culture about the disability or illness.**
- ✓ **Actions the family has or has not already taken to help their child, including traditional, family or medical interventions.**
- ✓ **The family's previous experiences accessing medical/health services and communicating with health providers.**

Recommendations:

1. Learn about the beliefs of the culture about disability and illness, as well as, the traditional treatment methods used.

2. Learn about your agency's experiences working with the cultural community. Were there successes? What types of problems did they encounter?

3. Take time to listen and learn about the family's perceptions and previous experiences. You can do this by asking a few simple questions, such as:

- ✓ What are your concerns?
- ✓ What have you already done to help your child?
- ✓ What can we do to help you?
- ✓ What do you hope will happen? Or what do you want to happen?

4. Remember to listen respectfully. Acknowledge the family's concerns, efforts and achievements.

5. Provide families with easy to understand medical explanations about the disability or illness. Also, help them to learn about the resources they can access, and how to access them.

"I'd recommend that a health care provider say, ' You know I'm really glad that you're here. I don't know a lot about your particular culture. If anything I say or do . . . makes you feel uncomfortable . . . tell me." (Parent)

Principle: Many cultures have defined ways to communicate and show respect for extended family, especially elder family members. Many cultures place a high value on formal communication interactions. Informality is considered disrespectful.

Recommendations:

1. Learn about the communication style of the culture and family. Be sensitive to the individual differences.

2. Greet, acknowledge and address communication to all family members. Remember that elders are highly respected in most cultures. Elders are often responsible for making the health care decisions regarding the child.

3. When meeting with families, find a room that is large enough to accommodate all family members. Also, try to find a room that is private. When possible, arrange seats so that there are not physical barriers, such as tables or desks.

4. It is better to be more formal when talking to family members. Address them using Mr. or Mrs., unless asked to do otherwise.

"To me one provider was helpful for me. And I guess it wasn't that she probably understood our culture, but she was more sensitive. And that part, where she seemed to give me more of the explanation . . . we kind of connected." (Parent)

"There was a doctor that we had on my home reservation in Michigan. And he was there for ten years. And he was just so much part of the community. And you know, I mean, he was just a special person. And the Indian people there just loved him. He was part of everything." (Parent)

Principle: In many cultures personal relationships are highly valued. Those relationships are based on trust and mutual respect. Changes in service providers may be considered a violation of that trust.

Recommendations:

1. When staff changes must occur, time should be allowed for transitioning activities which allow the family time to build trust in the new provider.

2. When it is not possible to have time for transitioning activities, time should be taken for a discussion with the family of the upcoming changes. During this discussion the providers should acknowledge the family's feelings about the change and the new provider. The providers should discuss with the family ways to make the transition more comfortable.

3. Learn about programs that have identified, trained and hired community members to work as case managers or community representatives. These community members can serve as liaisons between the families and providers. They provide consistency and can help when staff changes occur.

"I mean you fill out papers every time you go in. That same question. . . . Why would they want to know all these questions? . . ."

Principle: Many cultures have prescribed ways of talking about health and the human body. Asking questions is considered intrusive. The family may feel uncomfortable and may be offended.

Recommendations:

1. Review the questions and forms you use. Decide what information is needed.

2. Make sure that the environment in which you are talking is comfortable and private.

3. Explain to the family how the information you are collecting will be used to benefit their child. Also, take the time to explain what confidentiality means, and how the information they provide will be kept confidential.

4. Remember that many families are focused on the immediate health concern. They

may not understand the relationship between your questions and their concerns.

5. Ask the family which member of their family should answer the questions. Ask them if they need to discuss the questions with other family members before responding. Remember that in some cultures there are defined roles for family members, as well as, men and women.

6. Tell the family that they do not have to answer a question if they are uncomfortable or do not want to answer it. Also, it is okay if they want to talk to other family members before answering.

7. Learn about the perspective of the family and their culture regarding certain types of medical interventions or procedures. For example, how does the culture view surgical procedures, removal and disposal of body parts, burial. Discuss precautions, risk factors or potential complications.

8. Take time to explain to the family the requirements for signatures of agreement prior to interventions. Remember that in some cultures, the signing of papers is an action viewed with extreme caution.

"They would ask us all of these questions, and tell us that she has this. . . . And this is wrong. But we didn't know what they meant. We were just there and scared." (Parent)

Principle: **People who speak English as a second language find it more comfortable and easier to understand new or sensitive information in their native language. Although an interpreter is needed, the use of an interpreter who is *not "qualified" or not respected* by the cultural community can further inhibit communication.**

Recommendations:

1. Ask the family if they will need an interpreter. If possible, involve them in choosing the interpreter.

2. Select, train and hire interpreters who are bilingual-bicultural, and respected in the community. If an interpreter is not respected in the community, the family will feel uncomfortable and have concerns about confidentiality.

3. Conduct cross-cultural training for interpreters and the providers who will work with them. Topics which should be addressed as part of training are:

    ✓ confidentiality,
    ✓ medical terminology and concepts,
    ✓ cultural beliefs with respect to illness and disability, and ‘
    ✓ culturally appropriate ways to explain sensitive information.

4. When possible, the provider and interpreter should have a pre-meeting before they meet with the family. During this meeting they can review the information to be presented and discuss the best way to explain the information. If it is sensitive information, they can discuss potential reactions of the family based on cultural beliefs. The interpreter may advise the provider on the most culturally appropriate way to explain the information. For example, in some cultures sensitive information is presented in a less direct or “softened” form. Also, communication style including nonverbal and verbal communication should be discussed.

5. When appropriate and possible, the family should be encouraged to bring a bilingual family member or trusted friend who can provide support during the meeting. This person is not the interpreter, but can enhance or facilitate the interpretation process during the meeting and later in the home setting. This support person can increase family comfort and understanding. Remember, family members and friends should not be used as the primary health interpreter, because they lack training and they are personally involved.

Case Studies: Situations in Which Cultural Misunderstandings Often Occur and Possible Solutions

“Remember, we chose her the way she was. So she wasn’t even broken to us, but because they, her doctors, . . . talked us into a line of . . . we’ll fix them . . . . And nineteen years later, she’s not fixed. She’s still who she’s going to be forever.” (Parent)

Situation: **Cultures differ in their perspectives on disability and physical characteristics (e.g., weight, speech). Some cultures are more accepting of physical differences. In those cultures, health or therapeutic interventions may not be considered necessary or appropriate. Consequently, families may not see a problem that needs fixing. For example, some Hispanic/Latino, American Indian, and Southeast Asian cultures believe that children should be allowed to progress at their own pace. Parents should not try to change the natural progression. Children learn from the people around them and their environment.**

Suggestions:

1. Before recommending an intervention, learn about the family and culture's perspectives and values regarding disability, illness, and physical characteristics, such as ideal weight, fitness, gait, speech etc.. For example, in some Indian cultures being somewhat overweight is valued.

2. Learn from the family about their concerns. What do they want to happen?

3. Learn culturally appropriate methods (e.g., audio tapes, video tapes) to help the family to understand what can be achieved by interventions, such as therapy.

4. Allow the family to make their own decisions. Respect their decisions, even when you disagree.

5. If the family accepts the recommended intervention, be careful to progress at a pace that is comfortable for the family.

6. If the family desires, work with them to incorporate traditional practices into the intervention program.

Situation: **Some cultures do not value or use developmental milestones. Because of the diversity within cultural groups, there is not normative data on child development for every culture and language. For that reason, many African American families do not value tests based on white values. A Hispanic child whose family just immigrated from Central America may speak a very different Spanish and demonstrate developmental skills which are different from those of a Hispanic child who lives in northern New Mexico. Even within the Navajo tribe, the largest in North America, there are dialectical differences. Among the Southeast Asian cultures, there are significant differences in language and culture which impact child rearing practices and child development.**

Suggestions:

1. Learn the perspectives of the family and culture regarding child rearing and child development. Learn about the significant childhood events which are recognized and celebrated. Learn about the characteristics which are valued in children.

2. Work with other resource people who know the community and culture to gain information.

3. Ask the family how the child compares to other children within their family or community. Ask the family at what age they expect the child to do certain activities or to demonstrate specific skills.

4. When you ask questions about child development realize that the family may not recognize the same events as significant or they may interpret your questions in terms of their own experience. For example, speech-language therapists typically ask a family when their child said his first words. Some cultures interpret this to mean the time at which the child can converse with adults. In that situation, their answer to that question would be "when our child was three years old." That response would confuse the professional who interprets the question to mean the time when the child first began to say single words.

5. When standardized test instruments must be used to evaluate development, look for ways to modify those instruments so that they can be used with the population served. Also, collect data on characteristics of the population to whom you are providing services. For example, data should be collected on responses that are considered appropriate or typical for children at specific ages in the community.

"When a child was born with an extra digit, a skin tag on an ear lobe, or strabismus, the family often objected to correction of the condition. The reason was religious. 'It was meant to be.' They feared . . . if the child was cut, it might cause harm. If you cut into the eye, the child might become blind. For these seemingly simple procedures, it takes a careful, patient description and explanation. The provider must take the time to understand the family's attitude." (Asian consultant)

Situation: **Invasive practices which remove something from the body are considered inappropriate, in some cultures. For example, drawing body fluids, such as blood is in conflict with the beliefs of some Indian cultures. Removing a body part is in conflict with the beliefs of some Asian, Hispanic and Indian cultures. If the family does agree to the procedure, they may still feel uncomfortable.**

Suggestions:

1. Explain why the procedures is necessary or recommended. Discuss the benefits as well as the risk factors or complications which could occur.

2. If the procedure is not life threatening and time can be taken for decisions, give the family time to think about it and talk with other family members.

3. Acknowledge and show respect for the family's feelings, even when you disagree.

4. Discuss with the family comfortable ways in which they can be involved in the intervention procedure.

Situation: **Some families may be uncomfortable with physical examination and other interventions which require undressing. In some Asian and Indian cultures, there are cultural practices related to dressing and undressing.**

Suggestions:

When the child needs to be undressed for the purpose of examination or treatment,

1. Explain to the family why this procedures needs to be done.

2. Discuss with the family, who should undress the child, and who should be present or not be present. For example, if the child is a girl, it might be inappropriate for a male family member to be present.

"My daughter is diabetic, juvenile diabetic, and the problem I have is when we start talking diet. . . . I'd like to know how we can fit in what we eat culturally like our red beans and rice, our gumbos, and stuff like that. Tell me how to fix that to stay within the food exchange. " (Parent)

Situation: **Eating habits, food preferences, food preparation methods, and lifestyle are often culturally defined.**

Suggestion:

1. Before recommending a program, involving food or eating, take time to learn about the family and culture. For example, in some cultures:

   ✓ Dairy products are not eaten.
   ✓ Standard measurements are not used.
   ✓ Food is shared and meals are eaten in a communal style.
   ✓ Time is defined by daily events, not the clock.

2. Work with the family to find comfortable ways for them to incorporate recommended changes into their lifestyle.

3, Discuss with the family which foods are available to them. If recommended foods are not part of their normal diet or not available in their community, help them to identify appropriate foods which can be substituted.

Situation: **Medications may be resisted or schedules not followed. Many African American families are cautious about prescription drugs, particularly for the treatment of behavior disorders. In some cultures, they do not use standard measurement tools such as measuring spoons or clocks.**

Suggestion:

1. Before recommending medications, learn about the family's cultural perspective on medications.

2. Take time to explain to the family the reason why the medication is needed, the way in which it will benefit their child. Discuss any concerns or questions they might have.

3. Discuss with the family their lifestyle and how administration of the medication might be incorporated into their lifestyle. This is especially important if the family does not use clocks to guide their daily routine. It is also important to determine whether the family uses standard measurements. If they do not, they may need to be given the equipment they will need.

4. When medication is required to prevent recurrence of a condition, such as a seizure, the reason for continued use of the medication after the symptoms disappear should be explained carefully. Time should be taken to discuss the short and long term effects of the medication on the symptoms. Families should be told that even when the symptoms disappear they must continue to give the medicine. The time taken to do this can prevent misunderstanding and subsequent visits to the doctor or emergency room.